

AIDS Brief

for professionals

Politicians



Leadership, both political and public, appears to be a fundamental requirement for an effective response to HIV/AIDS, yet in countries around the world it is frequently identified as inadequate or absent. Politicians, regardless of the type of Government or political party to which they are affiliated, are the opinion-makers, role models and even the trend setters - an extraordinary responsibility when it comes to HIV/AIDS. This AIDS Brief describes the areas in which politicians can fulfil critical roles as visionaries, leaders, advocates, mobilisers and custodians of rights.

BACKGROUND

Definition of Politicians

A politician is variously defined as "one who is active in party politics", "one who is skilled in political governance or administration" or "a statesman who holds a political office".



With a few notable exceptions, politicians, like their Governments, have been reticent about becoming involved in HIV/AIDS. The reasons for this are multiple and include:

- Personal prejudices and discomfort with issues such as sex, sexuality, morality and mortality
- Inadequate information about an area that is developing rapidly
- That HIV/AIDS is perceived to be of relative unimportance in relation to other issues

- That it is not an issue with immediate and visible 'deliverables' such as lowered taxes
- That it is not a 'vote catcher', unlike issues such as access to water and electricity for all
- A reluctance to tackle the subject of HIV/AIDS, as it is a subject about which the electorate feel very strongly and sometimes irrationally, and around which they are often polarised
- The lack of a party position on the subject
- A myopia about the potential impact of AIDS on their portfolio, where this is not Health.

The reality however is that HIV/AIDS will impact on every aspect of life and no politician will be able to remain silent or uninvolved. Rather than responding reactively, without the opportunity of canvassing opinions and formulating considered opinions on the multitude of aspects which constitute the 'face of AIDS' in any country, it is suggested that politicians review how their various roles can be used to contribute to their country's efforts to address the HIV/AIDS epidemic.

KEY PERFORMANCE AREAS

Politicians have multiple roles – some of which have particular relevance in respect of HIV/AIDS. These are listed, with examples of how these roles can encompass HIV/AIDS.

Communication and the responsibility to be informed

Perhaps more than any other position in public life, politicians have the opportunity to communicate with vast numbers of people and to ensure that key messages are disseminated.

In the area of HIV/AIDS, this implies a responsibility to remain at the cutting edge of information, of scientific opinions and of popular debates. At the very least, politicians must be able confidently to discuss:

- What HIV/AIDS is
- How it can be treated
- Who is susceptible to infection
- What the impact will be
- What the future projections are
- What interventions can work and why

- What the national priorities are and why

Using the *Organisation of African Unity's Declaration on the AIDS epidemic in Africa* as a template, examples of key messages which could be adopted by politicians are the following:

- We must emphasise the gravity and urgency of the epidemic, and announce to our people that the country's stability and survival are at stake
- We must overcome any sensitivities and

speak out frankly about how to prevent AIDS; no taboo should be allowed to interfere with the saving of millions of lives

- We must counter the impression that AIDS is a disease that attacks only certain groups or populations, and show by our personal example that people with HIV or AIDS are to be treated with respect and compassion, in keeping with traditions of tolerance
- We must encourage traditional and religious leaders to exercise moral leadership to bring about life-saving changes in individual and collective behaviour
- We must seize this opportunity and ensure that today's girls and boys, who will be the mothers and fathers of tomorrow's children, are safe from HIV
- We must ensure links and collaboration between the formal health sector and community structures, including religious, charitable and other non-governmental organisations
- We must anticipate the family and community disruption that will result from AIDS deaths and plan now for ways of caring for and supporting the survivors

In speaking of HIV/AIDS it is important for politicians and their speech-writers to remember at all times the sensitivities associated with word choices. For example, avoid terms like 'AIDS victim' or 'sufferer', and use 'a person living with HIV or AIDS' instead. Take care with value-laden words and phrases like 'promiscuous', 'scourge', 'retribution' and 'immoral behaviour'. These feed a 'them and us' mentality which does nothing to assist and a great deal to harm efforts to normalise HIV/AIDS and to create an environment which is supportive of people who are infected or affected.

Decision-making, in the public interest

Politics involves decisions about who receives what, when, where and how. HIV/AIDS is an area where strategic decision-making must, in the first instance, be in the public interest (i.e. what is regarded as good for society or for people in general) as well as be appropriate and sustainable for the country in the long term.

Examples of strategic decisions could be:

- Supporting vaccine development or other HIV/AIDS research in a local community
- Approving access to treatments, such as antiretrovirals within the public health sector and within the country's financial constraints
- Forming alliances with youth organisations working with marginalised youth and approving access to condoms for the youth
- Challenging the private sector to implement workplace HIV/AIDS policies and programmes
- Committing Government resources to cross-border HIV/AIDS/STD initiatives

As HIV/AIDS is still an evolving epidemic, perhaps one of the most important decisions is to revisit strategic decisions on a regular basis and test their continued appropriateness.

Leadership

Politicians are elected in the main for their leadership qualities and on the basis of the promises which they make to the electorate. The stated positions on issues which appear in their manifestos are often contentious. Selecting HIV/AIDS as one of these issues could carry a significant risk, if, for example, the politician is perceived to be allying him or herself with certain groups in society (eg gay men, drug-users, sex workers etc). Yet HIV/AIDS is surely important enough to feature in every manifesto. The challenge would appear to be to ensure that HIV/AIDS is not politicised either as a party political issue or in terms of specific groups in society, but that it is accepted as an issue which transcends these – that it is a national emergency requiring a response such as would be mounted if the country's security were under threat.

Leadership on HIV/AIDS could take many forms, some more active than others. Examples include:

- Wearing a red ribbon at all public functions
- Speaking about HIV/AIDS at all opportunities
- Openly demonstrating acceptance of and solidarity with people living with HIV/AIDS
- Serving on national and local structures which deal with HIV/AIDS
- Supporting events such as World AIDS Day
- Leading rallies and adopting slogans such as *"Celebrate life – fight AIDS, not people with AIDS"*
- Engaging the media and other stakeholders on HIV/AIDS

Mass mobilisation

Mass mobilisation occurs when groups of people decide to take action. It generally does not happen spontaneously: instead it has its origin in some form of catalyst. A politician can act as such a catalyst, rallying people around a common cause.

Issues at the centre of mobilisation could be:

- Care and support for children orphaned by HIV/AIDS
- Disclosure by and acceptance of people living with HIV/AIDS
- Rights of HIV infected workers
- Improving the position and status of women
- Sectoral partnerships against HIV/AIDS
- Anti-AIDS campaigns in the armed forces
- Changing cultural practices or traditions that enhance the risk of HIV transmission

Governance

In the area of governance, politicians have a number of possible avenues which they can exploit.

- Within Government they have the authority to ensure that HIV/AIDS becomes a function of Government at all levels and at both a political and an administrative level
- They can initiate the development of positions/policies on HIV/AIDS by their political parties
- They can ensure that HIV/AIDS becomes an agenda item, for example at an all-party meeting for a Parliamentary debate and so on.

Rights and non-discrimination

Politicians, particularly in democratic countries which advocate the rights of all citizens, should understand where these rights may be in jeopardy for people living with HIV/AIDS, their partners, families and care-givers, and should endeavour at all times to promote a rights-based approach to dealing with the epidemic. The rights in question are well expressed in the CHARTER OF RIGHTS ON AIDS AND HIV which was drafted by experts in South Africa, drawing on international documents such as the Montreal Manifesto of the Universal Rights and Needs of People Living with HIV Disease and the United Kingdom Declaration of the Rights of People with HIV and AIDS. The Charter was launched on World AIDS Day, 1 December 1992.

Liberty, autonomy, security of the person and freedom of movement

- Persons with HIV or AIDS have the same rights to liberty and autonomy, security of the person and to freedom of movement as the rest of the population.
- No restriction should be placed on the free movement of persons within and between states on the ground of HIV or AIDS.
- Segregation, isolation or quarantine of persons in prisons, schools, hospitals or elsewhere merely on the ground of AIDS or HIV is unacceptable.
- Persons with HIV or AIDS are entitled to autonomy in decisions regarding marriage and child-bearing although counselling about the consequences of their decisions should be provided.

Confidentiality and privacy

- Persons with HIV or AIDS have the right to confidentiality and privacy concerning their health and HIV status.
- Information regarding a person's HIV status must not be disclosed without the person's consent, and, after death, except when required by law, without the consent of his or her family or partner, except in cases of clear threat to and disregard of an identifiable individual's life interests.

Testing

- HIV antibody testing must occur only with free and informed consent, except in the case of unlinked, anonymous epidemiological screening programmes.
- Anonymous and confidential HIV antibody testing with pre- and post test counselling should be available to all.
- Persons who test HIV positive should have access to continuing support and health services.

Education on AIDS and HIV

- All persons have a right to proper education and full information about HIV and AIDS, as well as the right to full access to and information about prevention methods.
- Public education with the specific objective of eliminating discrimination against persons with HIV or AIDS should be provided.

Employment

- HIV should not be a basis for pre-employment testing or a ground for refusing to employ any person.
- HIV or AIDS do not, by themselves, justify termination of employment or demotion, transfer or discrimination in employment.
- The mere fact that an employee is HIV positive or has AIDS does not have to be disclosed to the employer.
- There is no warrant for requiring existing employees to undergo testing for HIV.
- Information and education on HIV and AIDS, as well as access to counselling and referral, should be provided in the workplace after appropriate consultation with representative employee groups.

Health and support services

- Persons with HIV or AIDS have rights to housing, food, social security, medical assistance and welfare equal to all members of our society.
- Reasonable accommodation in public services and facilities should be provided for those affected by HIV or AIDS.
- The source of a person's infection should not be a ground for discrimination in the provision of health services, facilities or medication.

- HIV or AIDS should not provide the basis for discrimination by medical aid funds and services.

Media

- Persons with HIV or AIDS have the right to fair treatment by the media and to observance of their rights to privacy and confidentiality.
- The public has the right to informed and balanced coverage of, and the presentation of information and education on, HIV and AIDS.

Insurance

- Persons with HIV or AIDS, and those suspected to be "at risk" of having HIV or AIDS, should be protected from arbitrary discrimination in insurance.

Gender and sexual partners

- All persons have the right to insist that they or their sexual partners take appropriate precautionary measures to prevent transmission of HIV.
- The specially vulnerable position of woman in this regard should be recognised and addressed, as should the specially vulnerable position of youth and children.

Prisoners

- Prisoners with HIV should enjoy standards

of care and treatment equal to those of other prisoners.

- Prisoners with AIDS should have access to special care which is equivalent to that enjoyed by other prisoners with serious illness.
- Prisoners should have the same access to education, information and preventative measures as the general population.

Equal protection of the law and access to public benefits

- Persons with AIDS or HIV should have equal access to public benefits and opportunities, and HIV testing should not be required as a precondition for eligibility to such advantages.
- Public measures should be adopted to protect people with HIV or AIDS from discrimination in employment, housing, education, child care and custody and the provision of medical, social and welfare services.

Duties of persons with HIV or AIDS

- Persons with HIV or AIDS have the duty to respect the rights, health and physical integrity of others, and to take appropriate steps to ensure this where necessary.

CHECKLIST

Some key questions which can be asked to define a politician's role in respect of HIV/AIDS are as follows:

- ✓ Is HIV/AIDS one of your Government's or your personal priority issues? If not, should it be and how can it be elevated to become a priority issue?
- ✓ To what extent must Government or you personally depart from any stated position on morality in order effectively to address the reality of the epidemic?

- ✓ Do people living with HIV/AIDS have equal access to health care, employment, travel, housing and social welfare as non-infected citizens? If not, what can you do to correct this inequality?
- ✓ Are you working with all potential partners? If not, how can relationships be strengthened to ensure an optimal response to HIV/AIDS?
- ✓ To what extent are affected persons and communities participating meaningfully in HIV/AIDS initiatives and what can you do to

- improve and sustain their participation?
- ✓ How can you ensure that the 'bottom-up' experiences of people working in AIDS, which are critical to developing reactions which are responsive to the realities of AIDS, be heard and permitted to inform your position on HIV/AIDS issues?
- ✓ What sources of information are available to assist you to stay up-to-date about HIV/AIDS? What role can you play in keeping fellow politicians informed?

GUIDING PRINCIPLES

At the Paris AIDS Summit in 1994, 42 National Governments signed the following Declaration:

We the Heads of Government or Representatives of the 42 States assembled in Paris on 1 December, 1994:

1. MINDFUL that the AIDS pandemic, by virtue of its magnitude constitutes a threat to humanity, that its spread is affecting all societies that it is hindering the social and economic development, in particular of the worst affected countries, and increasing disparities within and between countries, that poverty and discrimination are contributing factors in the spread of the pandemic, that HIV/AIDS inflicts irreparable damage on families and communities, that the pandemic concerns all people without distinction but that women, children and youth are becoming infected at an increasing rate, that it not only causes physical and emotional suffering, but is often used as a justification for grave violations of human rights,

MINDFUL ALSO that obstacles of all kinds – cultural, legal, economic and political – are hampering information, prevention, care and support efforts, that HIV/AIDS prevention and care support strategies are inseparable, and hence must be an integral component of an effective and comprehensive approach to combating the pandemic, that new local, national and international forms of solidarity are emerging, involving in particular people living with HIV/AIDS and community based organisations,

2. SOLEMNLY DECLARE our obligation as political leaders to make the fight against HIV/AIDS a priority, our obligation to act with compassion for and in solidarity with those with HIV or at risk of becoming infected, both within our societies and internationally, our determination to ensure that all persons living with HIV/AIDS are able to realise the full and equal enjoyment of their fundamental rights and freedoms without distinction and under all

circumstances, our determination to fight against poverty, stigmatisation, and discrimination, our determination to mobilise all of society – the public and private sectors, community based organisations and people living with HIV/AIDS – in a spirit of true partnership, our appreciation and support for the activities and work carried out by multilateral, intergovernmental, non-governmental and community based organisations, and our recognition of their important role in combating the pandemic, our conviction that only more vigorous and better co-ordinated action worldwide, sustained over the long term – such as that to be undertaken by the joint and co-sponsored United Nations Programme on HIV/AIDS – can halt the pandemic.

3. UNDERTAKE IN OUR NATIONAL POLICIES TO protect and promote the rights of individuals, in particular those living with or most vulnerable to HIV/AIDS, through the legal and social environment, fully involve non-governmental

and community based organisations as well as people living with HIV/AIDS in the formulation and implementation of public policies, ensure equal protection under the law for persons living with HIV/AIDS with regard to access to health care, employment, travel, housing and social welfare, intensify the following range of essential approaches for the prevention of HIV/AIDS:

- promotion of and access to various culturally acceptable prevention strategies and products, including condoms and treatment of sexually transmitted diseases,
- promotion of appropriate prevention education, including sex and gender education, for youth in school and out-of-school,
- improvement of women's status, education and living conditions,
- specific risk-reduction activities for and in collaboration with the most vulnerable populations such as groups at high risk of sexual transmission and migrant populations,
- the safety of blood and blood products,
- strengthen primary health care systems as a basis for prevention and care, and integrate HIV/AIDS activities into these systems, so as to ensure equitable access to comprehensive care,
- make available necessary resources better to combat the pandemic, including adequate support for people infected with HIV/AIDS, non-governmental organisations and community based organisations working with vulnerable populations.

4. ARE RESOLVED TO STEP UP THE INTERNATIONAL CO-OPERATION THROUGH THE FOLLOWING MEASURES AND INITIATIVES. We shall do so by providing our commitment and support to the development of the joint and co-sponsored United Nations Programme on HIV/AIDS, as the appropriate framework to reinforce partnerships between all involved and give guidance and worldwide leadership in the fight against HIV/AIDS. The scope of each initiative should be further defined and developed in the context of the joint and co-sponsored Programme and other appropriate fora:

- (i) Support a greater involvement of people living with HIV/AIDS through an initiative to strengthen the capacity and co-ordination of networks of people living with HIV/AIDS and community based organisations. By ensuring their full involvement in our common response to the pandemic at all - national, regional and global - levels, this initiative will, in particular, stimulate the creation of supportive political, legal and social environments.
- (ii) Promote global collaboration for HIV/AIDS research by supporting national and international partnerships between the public and private sectors, in order to accelerate the development of prevention and treatment technologies, including vaccines and microbicides, and to provide for the measures needed to help ensure their accessibility in developing countries. This collaborative effort should include related social and behavioural research.
- (iii) Strengthen international collaboration for blood safety with a view to co-ordinating technical information, proposing standards for good manufacturing practice for all blood products, and fostering the establishment and implementation of co-operative partnerships to ensure blood safety in all countries.
- (iv) Encourage a global care initiative so as to reinforce the national capability of countries, especially those in greatest need, to ensure access to comprehensive care and social support services, essential drugs and existing preventive methods.
- (v) Mobilise local, national and international organisations assisting as part of their regular activities children and youth, including orphans, at risk of infection or affected by HIV/AIDS, in order to encourage a global partnership to reduce the impact of the HIV/AIDS pandemic upon the world's children and youth.
- (vi) Support initiatives to reduce the vulnerability of

women to HIV/AIDS by encouraging national and international efforts aimed at the empowerment of women; by raising their status and eliminating adverse social, economic and cultural factors; by ensuring their participation in all the decision-making and implementation processes which concern them; and by establishing linkages and strengthening the networks that promote women's rights.

(vii) Strengthen national and international mechanisms that are concerned with HIV/AIDS related human rights and ethics, including the use of an advisory council and national and regional networks to provide leadership, advocacy and guidance in order to ensure that non-discrimination, human rights and ethical principles form an integral part of the response to the pandemic.

We urge all countries and the international community to provide the resources necessary for the measures and initiatives mentioned above.

We call upon all countries, the future joint and co-sponsored United Nations Programme on HIV/AIDS and its six member organisations and programmes to take all steps possible to implement this Declaration in accordance with other multilateral and bilateral aid programmes and intergovernmental and non-governmental organisations.

Countries which were represented at the Paris Summit and signed the Declaration were: Argentina, Australia, Bahamas, Belgium, Brazil, Burundi, Cambodia, Cameroon, Canada, China, Côte d'Ivoire, Denmark, Djibouti, Finland, France, Germany, India, Indonesia, Italy, Japan, Mexico, Morocco, Mozambique, Netherlands, Norway, Philippines, Portugal, Romania, Russian Federation, Senegal, Spain, Sweden, Switzerland, United Republic of Tanzania, Thailand, Tunisia, Uganda, United Kingdom, United States of America, Vietnam, Zambia, Zimbabwe.

SUMMARY

HIV/AIDS is one problem among many that confront policy-makers and politicians whilst being less visible and more challenging than others. Politicians must often balance

opposing viewpoints; challenge discrimination; show support for people living with HIV/AIDS; and mobilise communities to respond appropriately. Only then will the leadership so

earnestly sought become a reality and a foundation upon which to build a country's response. History and future generations will judge our endeavours and achievements.

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Prepared by: Rose Smart, HIV/AIDS Consultant, South Africa

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Commissioning Editor: Professor Alan Whiteside, Health Economics and HIV/AIDS Research Division, University of Natal, Durban, South Africa

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